

HCCA

Hereditary Colon Cancer Association



*To Educate, Support,
Provide for Today
and Protect the Future*

June 18, 2001

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The Honorable Congressman John Dingell,
Ranking Member,
House Energy and Commerce Committee

Dear Congressman Dingell:

The Hereditary Colon Cancer Association supports your efforts to pass the "Patient Rights Bill," House Bill 526. We are particularly interested in the sections of the bill which address accessibility to clinical trials for patients which currently incurable diseases and accessibility to specialists outside HMO and PPO networks.

The patients and families for whom we are an advocate struggle with rare diseases such as Familial Adenomatous Polyposis which can begin in childhood and will lead to colon cancer, if undiagnosed, in the third or fourth decade of life. Another is Peutz-Jegher Syndrome which is linked with colon cancer; breast, cervical and ovarian cancers; testicular cancer; and pancreatic cancer. There are 4 other diseases, each one more or less deadly than these. Because they are rare, it is essential for the families that must deal with them to have access to participation in, and to receive the experimental protocol yielded by, clinical trials. They must be able to consult with and receive treatment from specialists familiar with their diseases. Too many families tragically lose members at a young age—even in childhood—unnecessarily because the only doctors they could access in their networks knew nothing about the rare diseases.

Thank you for your efforts in making appropriate and effective health care more readily accessible to thousands of American citizens. We wish you well for a speedy passage of this bill.

Sincerely yours,

Kathy Kersey
HCCA Director of Operations